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FULL-LENGTH ORIGINAL RESEARCH

Epilepsia

Access to diagnostic and therapeutic facilities for psychogenic nonepileptic seizures: An international survey by the ILAE PNES Task Force

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Summary

Objective: Studies from a small number of countries suggest that patients with psychogenic nonepileptic seizures (PNES) have limited access to diagnostic and treatment services. The PNES Task Force of the International League Against Epilepsy (ILAE) carried out 2 surveys to explore the diagnosis and treatment of PNES around the world.

Methods: A short survey (8 questions) was sent to all 114 chapters of the ILAE. A longer survey (36 questions) was completed by healthcare professionals who see patients with seizures. Questions were separated into 5 sections: professional role, diagnostic methods, management, etiology, and access to health care.

Results: Responses were received from 63 different countries. The short survey was completed by 48 ILAE chapters, and the long survey by 1098 health professionals from 28 countries. PNES were recognized as a diagnostic and therapeutic problem in all countries. Trauma and mental health issues were most commonly recognized as etiologic factors. There was a clear relationship between income and access to diagnostic tests and expertise. Psychological therapy was most commonly considered the treatment of choice. Although financial difficulties were the most commonly reported problem with service access in low-income countries, in all countries stigma, lack of popular awareness, and lack of information posed challenges.

Significance: This global provider survey demonstrates that PNES are a health problem around the world. Health care for PNES could be improved with better education of healthcare professionals, the development of reliable and simple diagnostic procedures that do not rely on costly tests, and the provision of accessible information.

KEYWORDS

diagnostic methods, dissociation, psychogenic nonepileptic seizures, psychopathology, therapeutic strategies

1 | INTRODUCTION

Psychogenic nonepileptic seizures (PNES) are a common differential diagnosis of epilepsy, with a prevalence estimated at 50/100 000.[1] People with PNES usually present to the same health service providers as those with epilepsy. For these reasons, the International League Against Epilepsy (ILAE) appointed a PNES Task Force. Having previously provided guidance on the diagnostic process and summarized current knowledge on management,[2,3] this Task Force turned its attention to provisions for PNES around the world.

Anecdotal and historical accounts suggest that PNES-like states are a ubiquitous phenomenon and not a product of modern or developed society.[4–6] Nonetheless different sociocultural groups appear to understand PNES-like behaviors in different ways,[7] and at least some etiologic factors may differ among cultures.[1,8]

Despite widespread recognition of PNES and consensus on the diagnostic process,[3] diagnostic delays are common. Although delay in poorer regions may be explained by poor access to appropriate expertise or to video–electroencephalography (EEG) facilities,[6] significant problems with the timely recognition of PNES have also been documented in richer countries,[9] and studies from such countries have indicated considerable regional variability of diagnostic service provision.[10,11]

Variability of provision also appears marked in terms of access to treatment. A number of studies suggest that psychological treatment is beneficial for many patients,[12–14] and most neurologists consider psychological therapy the treatment of choice.[10,11] However, even in a relatively affluent country like the United Kingdom, only one-third of practitioners can refer all their patients for psychological treatment, and 1 in 6 neurologists reports being unable to refer any patients at all.[10]

To provide an overview of the diagnostic and therapeutic facilities available for PNES around the world, the ILAE PNES Task Force designed 2 surveys for healthcare professionals. One short survey was sent to all national ILAE chapters (ie, national representatives). A more detailed survey was targeted primarily to healthcare practitioners from 9 countries with very different socioeconomic characteristics. In this report we summarize the findings of both surveys, describe provisions for patients with PNES around the world, and relate provision of services to the economic status of different countries.

Key Points

- PNES are recognized as an important health problem around the world
- There is a clear relationship between access to diagnostic and treatment services for PNES and a country's economic status
- Psychological treatment is considered the treatment of choice for PNES around the world
- Stigma, suboptimal education of healthcare professionals, and lack of popular awareness and information are key challenges around the world

2 | METHOD

2.1 | Survey description

Both surveys were composed in English and approved for use and distribution to all ILAE chapters by the members of the Commission on Neuropsychobiology of the ILAE and the Executive Committee.

2.1.1 | Short survey

An 8-question ("short") survey (see Appendix S1) was sent to all chapters of the ILAE, asking for information on healthcare provision for PNES in their country.

2.1.2 | Detailed survey

A detailed 36-question ("long") survey was designed for providers of care for PNES (doctors, nurses, psychologists or psychotherapists, and others). The "long" survey was based on an original survey originally administered to members of the American Epilepsy Society (AES).[11] Similar surveys were later used to assess provision in other countries (Chile and Brazil)[15,16] before the survey was adapted for this project by the ILAE PNES Task Force.

The questions in the "long" survey were in 5 sections: (1) the role of the respondent and their exposure to PNES, (2) diagnostic methods, (3) management of PNES, (4) perceived etiologic factors, and (5) perceived problems accessing health care (see Appendix S2). Members of the Task Force acted as survey leads, aiming to recruit responses from as many PNES-involved healthcare professionals as possible, using the membership registers of the ILAE or other relevant professional organizations, as well as personal contacts. Although different individuals responding from a single center may have shaped one another's views of PNES or local treatment practices, we were keen to capture as many individual views as possible and therefore did not take any measures to restrict the number of respondents from the same center. The survey was translated by survey leads for use in France, Japan, Georgia, and Chile. Additional responses received from some other countries were included (see Table 1).

Both surveys were administered using SurveyMonkey, an Internet-based survey platform. Potential participants received a link to the survey by email. Where familiarity with online survey software was limited, Microsoft Word (Microsoft, Redmond, WA, USA) versions of the survey were posted, allowing respondents to return their response to the country survey lead by email or in the form of hard copies (eg, Georgia).

Ethical approval was obtained by leads in countries that required it (South Africa, United States). The study was conducted in accordance with Good Clinical Practice procedures and the current revision of the Declaration of Helsinki.

2.2 | Socioeconomic classification of countries

Countries were ranked economically according to 2014 per capita gross national income (GNI), calculated using the World Bank Atlas method.[17] For the purpose of this report, we defined 3 groups: (1) low-income (LI; less than $4126), (2) middle-income (MI; $4126-12 735), and (3) high-income (HI; $12 736 or more) countries.

2.3 | Analysis and statistics

Descriptive analyses were used to summarize key findings. Responses to the 4 questions common to the short and long surveys were combined. Responses based on the long survey reflect the median of the range of replies. The median response was also used when information was available about a country from the "long" and "short" surveys. Responses to questions 4 and 5 of both surveys were not reported because it was evident that respondents had interpreted these questions in different ways.

The denominator varies between items because we only report answers to questions relating to the diagnosis or treatment of PNES from respondents who described themselves as being involved in the corresponding aspects of

TABLE 1 Responses from different countries according to their economic wealth

World bank classification	Long survey (28 countries, 1098 participants)	Short survey (48 participants)
Low-income countries (countries: n = 13; respondents: n = 144)	Zambia (87)[a], Georgia (41), India (4), Philippines (1)	Egypt (1), Georgia (1), Ghana (1), India (1), Kyrgyzstan (1), Morocco (1), Pakistan (1), Republic of Moldova (1), Syria (1), Tanzania (1), Ukraine (1)
Middle-income countries (countries: n = 18; respondents: n = 99)	South Africa (69), Brazil (4), Turkey (4), Colombia (3), Costa Rica (1), Iran (1), Lebanon (1), Peru (1), Thailand (1)	Bosnia and Herzegovina (1), Brazil (1), Colombia (1), China (1), Costa Rica (1), Croatia (1), Iraq (1), Jordan (1), Macedonia (1), Malaysia (1), Serbia and Montenegro (1), South Africa (1), Tunisia (1), Turkey (1)
High-income countries (countries: n = 32; respondents: n = 903)	USA (467), France (129), United Kingdom (89), Canada (66), Japan (66), Chile (51), Australia (2), Ireland (2), Saudi Arabia (2), Argentina (1), Israel (1), New Zealand (1), Spain (1), Switzerland (1), Uruguay (1)	Argentina (1), Austria (1), Cyprus (1), Denmark (1), Finland (1), France (1), Germany (1), Hungary (1), Ireland (1), Kuwait (1), Latvia (1), Lithuania (1), Malta (1), Netherlands (1), New Zealand (1), Norway (1), Poland (1), Qatar (1), Saudi Arabia (1), South Korea (1), Sweden (1), Switzerland (1), Taiwan (1)

[a] Number of responses from each country.

care provision. Pearson *r* was used to calculate correlations between variables.

3 | RESULTS

3.1 | Participating countries

The "short" survey was completed by ILAE chapters representing 48 countries from 6 continents. The "long" survey was completed by 1098 health professionals from 28 countries. Brief descriptions of the healthcare systems of the 9 countries primarily targeted (United States, France, United Kingdom, Zambia, South Africa, Japan, Canada, Chile, Georgia) are provided in Table S1. Respondents from HI countries were overrepresented in the "long" survey: 880 were received from 15 HI countries, 85 from 9 MI countries, and 133 from 4 LI countries (see Table 1 for details). In total this report includes responses from 63 countries.

3.2 | Description of the sample

3.2.1 | Sociodemographics

Overall, more respondents to the "long" survey were male (54%). The median age range of respondents was 41 to 50 years (range 21 to 80). Respondents from LI countries were younger (median age range 31 to 40 years), and more often female (58%).

3.2.2 | Training and specialization

Most respondents (80%) worked in hospitals and regarded themselves as fully trained (HI, 95; LI, 82%). Psychiatrists made up a large proportion (42%) of respondents in MI countries, and a smaller contribution from LI (8%) and HI (5%) countries. Psychotherapists or psychologists provided 8% of responses from LI, 27% from MI, and 2% from HI countries. Other specialists (predominantly pediatricians) provided a mean of 8% of all responses, whereas nurses provided only 4% (Table S2).

In HI countries, more responses (71%) were returned by highly specialized doctors (eg, neurologists with special interest in epilepsy) than by generalists (16%, eg, general neurologists or physicians), whereas more responses from LI countries were returned by generalists than specialists (26% vs 15%).

3.2.3 | Exposure to PNES and pattern of practice

Most respondents (62%) diagnosed more than 6 patients with PNES per year. The proportion diagnosing more than 20 patients per year was 16% in LI, 11% in MI, and 28% in HI countries. More respondents in LI countries (30%) than in MI (23%) or HI countries (12%) stated that they had no current patients with PNES.

When asked to describe their role in PNES, respondents from HI and MI countries more commonly stated that they diagnosed PNES (75-82%), communicated the diagnosis (68-82%), recommended treatment (55-61%), and offered follow-up (55-60%). Among respondents from LI countries, only 31% stated that they diagnosed PNES, 29% that they communicated the diagnosis, 19% that they recommended treatment, and 22% that they offered follow-up. More respondents from LI countries (59%) stated that they referred patients to another physician when the diagnosis of PNES was suspected, than from MI (25%) or HI (15%) countries. Across respondents there was a positive correlation between the number of patients diagnosed per year and the level of confidence ($r = .51$, $P < .0001$).

The level of diagnostic confidence also appeared to vary with national income: the percentage of practitioners who described themselves as "not familiar" with the diagnosis of PNES or unable to distinguish between PNES and epilepsy was higher in LI (44%) than in MI (12%) and HI (6%) countries (see Figure 1).

A similar pattern was seen regarding confidence about treatment. The percentage of practitioners declaring themselves as able to arrange treatment was lower in LI (37%) compared to MI (42%) or HI (57%) countries. Although only a minority of respondents from all country categories described themselves as familiar with psychotherapy for PNES, practitioners from HI countries (30%) and MI countries (37%) did so somewhat more frequently than those from LI countries (20%) (Table S2). There was a positive correlation between the number of patients under the current care of respondents and their confidence about treating PNES ($r = .33$, $P < .0001$).

3.2.4 | Patient profile

Most respondents from LI countries (86%) stated that they saw patients of all ages, compared to 53% in HI countries. Respondents from HI countries were more likely to see patients with intellectual disability (82%) than those from LI countries (53%).

In all countries, respondents reported that they saw PNES more commonly in women than in men (75%), although 17% reported no gender preponderance. No respondent from an LI country stated that their patients could receive state disability benefits for PNES, compared to 23% in MI and 50% in HI countries (Table S2 for further details).

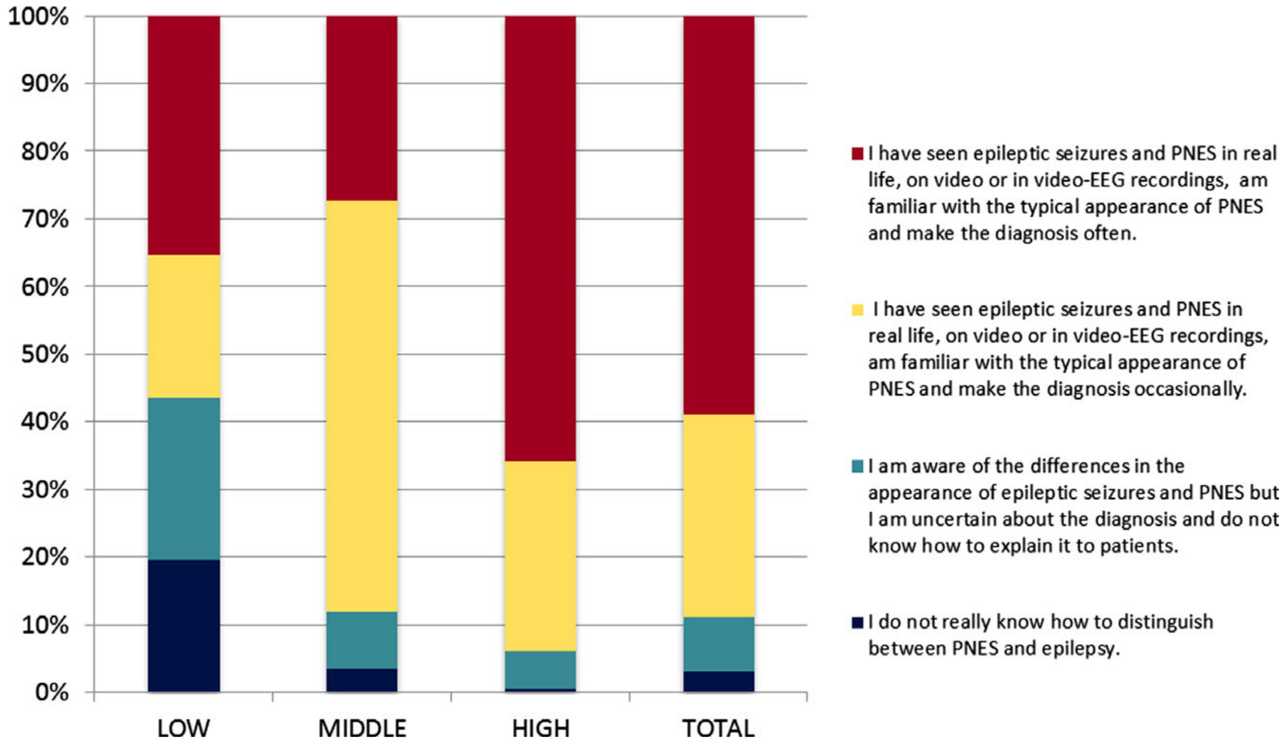

FIGURE 1 Level of confidence about the diagnosis of PNES

3.3 | Diagnostic issues

3.3.1 | Diagnostic methods

Most respondents to the "long" survey (69%) stated that they "personally diagnose PNES" (LI, 31%; MI, 75%; HI, 82%). In HI countries, 82% of those who "personally diagnose PNES" described themselves as neurologists with a special interest in epilepsy, versus 30% in MI and 29% in LI countries. General neurologists or psychiatrists were more likely to diagnose PNES in MI (31% and 37%) and LI (27% and 27%) than in HI countries (15% and 5%) (see Table S3 for further details).

Tests available to more than 70% of the respondents who diagnose PNES included routine EEG with or without video (78%), inpatient video-EEG monitoring for over 8 h (81%), neuropsychological testing (83%), computed tomography (CT; 83%), magnetic resonance imaging (MRI; 87%), routine electrocardiography (ECG; 83%) and 24-h ambulatory ECG (75%). Respondents' mean estimate of the proportion of patients whose diagnosis of PNES was supported by recording a typical attack on video-EEG was 80% in HI, 30% in MI, and 2% in LI countries, showing a clear relationship between wealth category and the availability of this test (see Figure 2).

3.3.2 | Psychological assessment

Psychiatric/neuropsychiatric assessments were reportedly carried out more often in MI countries (100%) than in HI (80%) or LI (50%) countries. Survey respondents indicated that few patients undergo a psychotherapeutic or (neuro-)psychological assessment in LI countries (10-20%), whereas respondents in MI and HI countries noted that it was used more often in their countries (40-80%; see Table S3 for further details).

3.3.3 | Communicating the diagnosis

Most (816/1098, 74%) respondents to the "long survey" stated that they personally communicate the diagnosis of PNES (LI, 29%; MI, 68%; HI, 82%). The diagnosis was reportedly communicated most often by neurologists in HI countries (94% vs 33% in LI countries) and psychiatrists in LI countries (66% vs 5% in HI countries).

Among respondents who personally communicated the diagnosis of PNES, face-to-face explanation was selected as the predominant method (93%). Additional methods of communication were reportedly used by only a minority of respondents, even in HI countries. The practice of writing a letter to another healthcare professional was reportedly more common in HI than in LI countries (28 vs 3%),

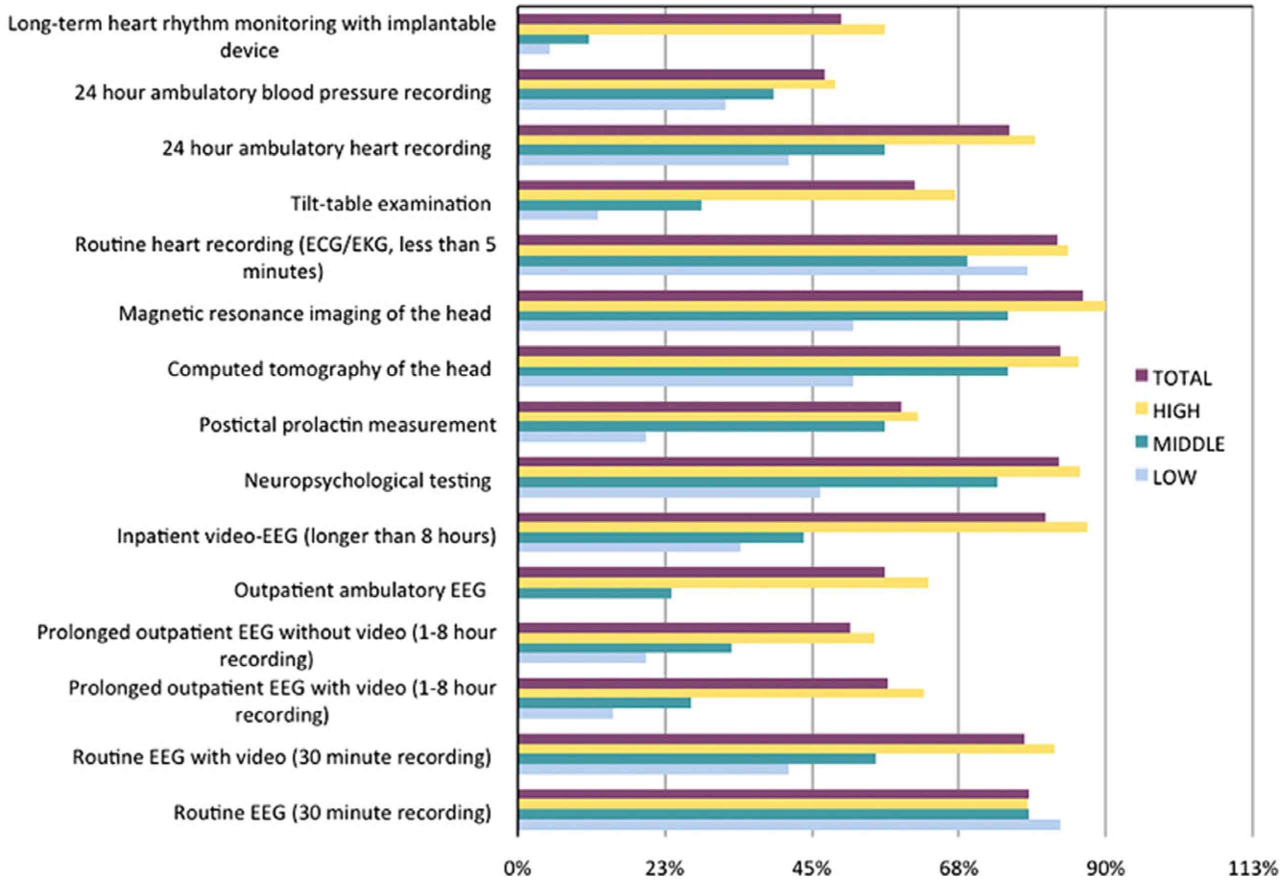

FIGURE 2 Access to diagnostic tests in different country categories

similarly to giving the patient a leaflet (28 vs 5%), or referring them to PNES websites (18 vs 0%).

In their explanation of PNES, most healthcare professionals reported mentioning stress (LI, 50%; MI, 59%; HI, 69%), trauma (LI, 8%; MI, 31%; HI, 40%), the fact that the patient was not deliberately producing PNES (LI, 82%; MI, 64%; HI, 78%), and that antiepileptic drugs do not work for PNES (LI, 61%; MI, 52%; HI, 80%). Respondents from LI and MI countries were less likely to state than those from HI countries that they provide patients with an etiologic explanation (See Table S3 for further details).

3.4 | Management of PNES

The majority (567/1098, 74%) of all respondents to the "long" survey reported that they provide follow-up or treatment for PNES (LI, 22%; MI, 60%; HI, 55%). In HI countries, neurologists with a special interest in epilepsy were most likely to select this (78%), compared to 23% in MI and 20% in LI countries. Psychiatrists were thought to be less likely to provide treatment for PNES patients in HI (7%), than in MI (51%) or LI countries (34%). Recourse to traditional healers (7%) was reported only in LI countries (See Table S4).

3.4.1 | Follow-up

Respondents estimated that they offered 80% of their patients at least one visit after diagnosis, more frequently in LI and MI (LI, 95%; MI, 95%) than in HI countries (80%). The 2 main reasons given for providing follow-up were comorbid epilepsy (LI, 31%; MI, 60%; HI, 82%), and antiepileptic drug reduction (LI, 21%; MI, 42%; HI, 62%).

3.4.2 | Treatment

Most (977/1098, 89%) respondents considered one-to-one psychological therapy the most effective treatment for PNES (LI, 73%; MI, 95%; HI, 92%). Group psychotherapy was considered most effective by 14% from LI countries, compared to only 1% in MI and HI countries. Antidepressant drugs were considered most effective by 5% of all practitioners.

This question offered respondents an "other" category. In Japan, 40% of participants entered "environmental control," an approach aiming to reduce environmental (eg, family and work) stress. No respondent from any other country entered a form of treatment resembling environmental control.

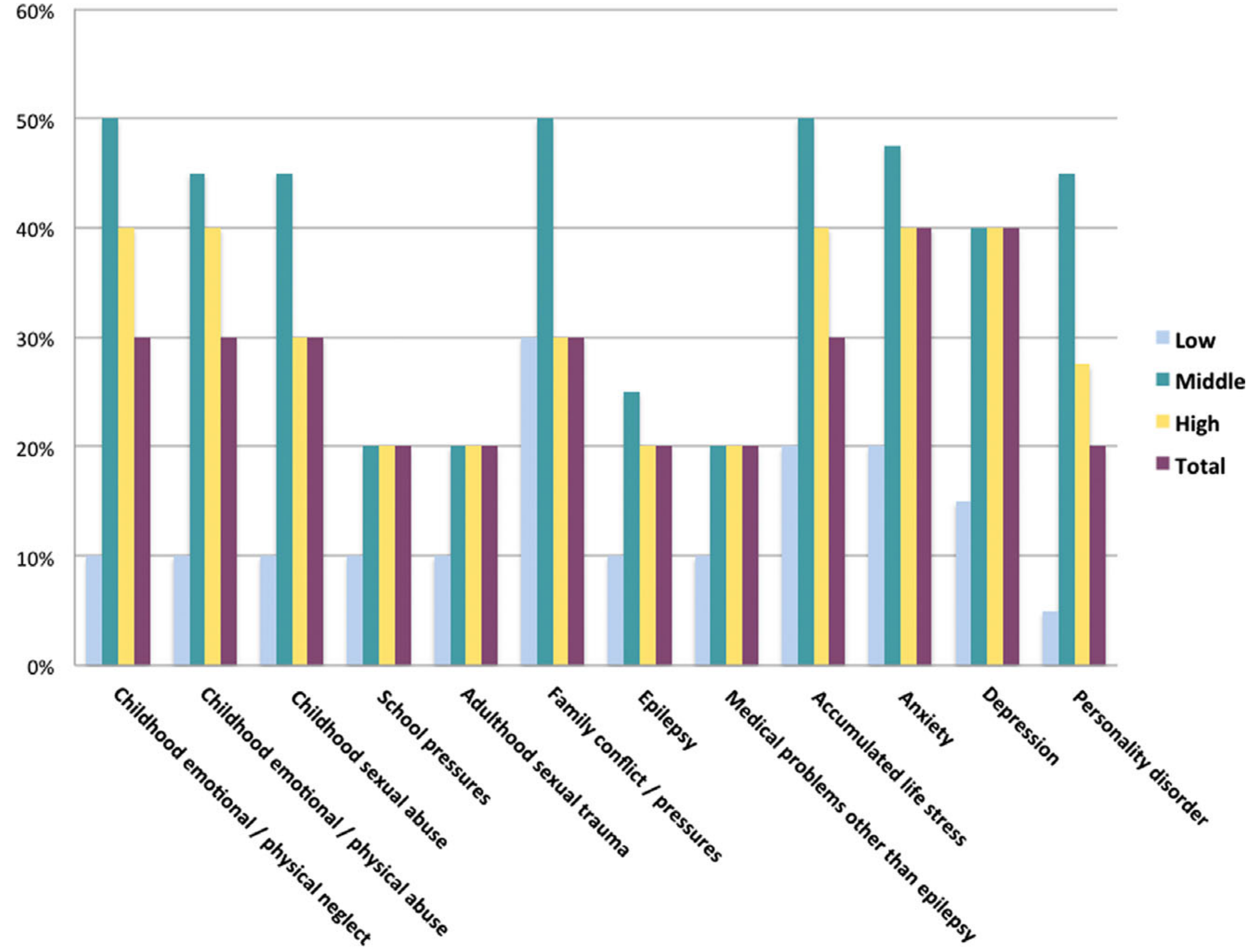

FIGURE 3 Major etiologic factors

Respondents from 63 countries (both surveys combined) estimated the proportion of patients with PNES offered at least one appointment for psychological treatment as 80% in HI countries, 35% in MI countries, and 50% in LI countries (See Table S4 for further details).

3.5 | Etiologic factors

Etiologic factors most commonly recognized by respondents were anxiety (median response across countries: 40%, range 20-70%), depression (40%, 20-60%), childhood abuse or neglect (30%, 10-60%), family conflict/pressures (30%, 20-50%), and accumulated life stress (30%, 10-60%) (Figure 3).

A median of 20% of survey participants endorsed epilepsy, personality disorders, and sociocultural factors (eg, poverty, religious, and cultural factors) as perceived etiologic factors. In MI, 40% of participants considered poverty a likely etiologic factor (see Table S5 for further details).

3.6 | Problems accessing health care

3.6.1 | Healthcare funding

Responses suggested that PNES patient care was provided on a self-pay basis in 50% of patients in LI countries, 10% in MI, and 5% in HI countries. Social insurance or government health care was reported to pay for 15% of PNES medical costs in LI countries, 80% in MI, and 60% in HI countries. Private insurance was stated to be available for hardly any patients in LI countries, 20% in MI, and 30% in HI countries (see Table S6 for further details).

3.6.2 | Psychological care

According to responses to the long survey, psychological treatment is not available in areas represented by 38% of respondents from LI countries, compared to 2% from MI and 6% from HI countries. Psychotherapy was reported to be available for most publicly insured patients in HI (65-75%) and but rarely available in LI countries (10%).

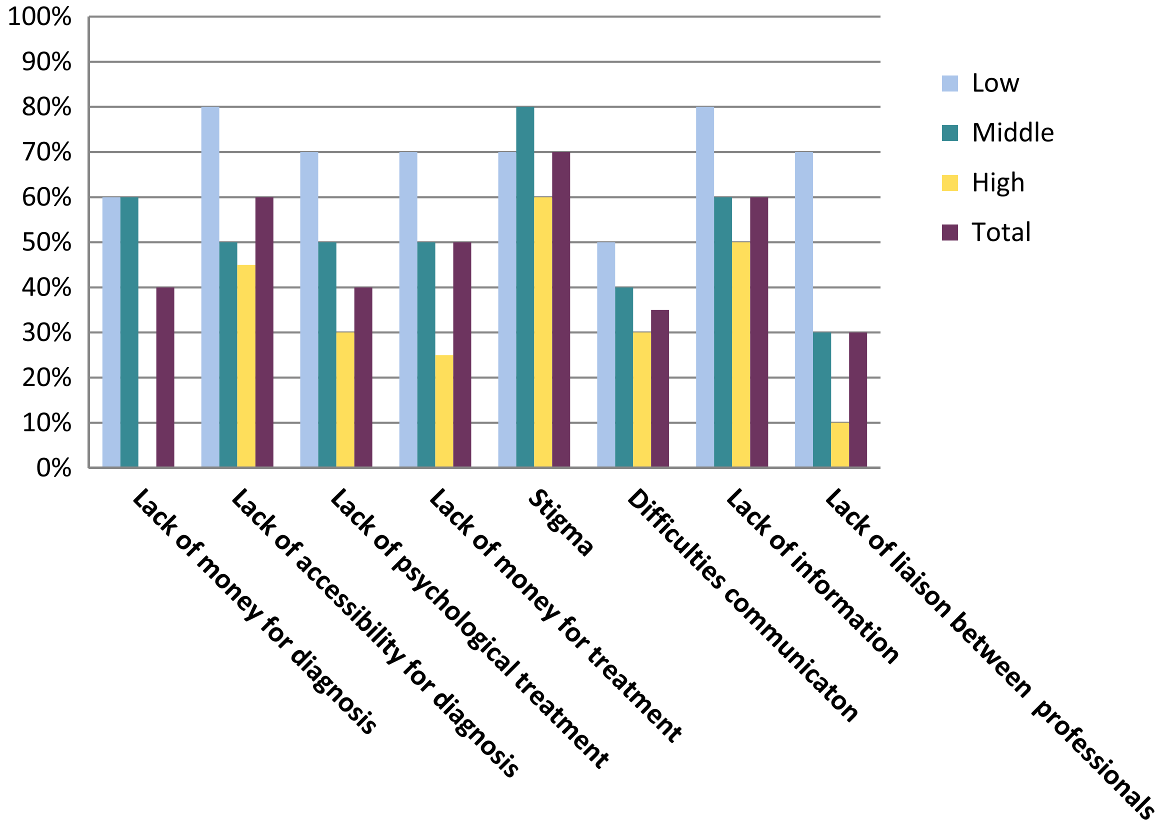

FIGURE 4 Major hurdles to the diagnosis and treatment of PNES around the world

3.6.3 | Key challenges

According to the responses provided in the "short" survey only, the most commonly identified barriers to the diagnosis and treatment for PNES were stigma/lack of awareness of PNES (identified in 70% of countries), lack of access to information (60%), and lack of money for treatment (60%).

The most commonly perceived problems with access to diagnosis and treatment in LI countries (estimated to affect 60-80% of patients) were lack of diagnostic services, psychological treatment, and money for treatment, as well as stigma/lack of awareness or information. In HI countries the most commonly reported barriers were stigma (estimated to affect 60% of patients), lack of information (50%), lack of access to diagnostic services (45%), and lack of specialist expertise (Figure 4) (see Table S6 for further details).

4 | DISCUSSION

This is the first international study surveying providers around the world regarding diagnostic and treatment services for PNES. Respondents from 63 countries on 6 continents recognized PNES as a common differential diagnosis of epilepsy. As expected, the results suggested that patients in rich countries have better access to relevant services. However, even in wealthier countries the responses to the surveys provided evidence of significant variation in access to good diagnosis and treatment. Stigma, lack of awareness of and information about PNES were identified as major challenges.

4.1 | Expertise of healthcare professionals

The responses to our surveys suggested that PNES diagnoses tend to be made by more highly specialized professionals in HI countries. These specialists were also more confident about their diagnostic abilities. Based on our surveys, patients in LI countries are likely to face considerable difficulties with accessing specialists with relevant diagnostic expertise and equipment. Greater subspecialization and better access to diagnostic and treatment facilities may both have contributed to the better diagnostic confidence reported by HI country respondents.

4.2 | Diagnostic tests

Not surprisingly, we found a clear relationship between national income and availability of diagnostic tests. Access to video-EEG, the gold standard for the diagnosis of PNES, emerged as uneven across countries and particularly limited in LI countries. This diagnostic access gap highlights the global importance of utilizing diagnostic strategies that do not necessarily depend on equipment and expertise that are not available, presently.[3]

4.3 | Psychological assessment

Despite the fact that psychological or psychiatric assessments were most likely to be available in HI countries, it was interesting to note that fewer patients seemed to be referred for such assessments than in MI countries. This may reflect the fact that some neurologists continue to consider their role as limited to the exclusion of epilepsy rather than as charged with making a more comprehensive diagnosis involving the identification of possible etiologic factors and psychiatric comorbidities, although our survey questions did not directly address this.

4.4 | Communicating the PNES diagnosis

A clear and acceptable explanation of PNES is a key step in the therapeutic process and may have a significant effect on prognosis.[18–20] For a subset of patients, this explanation may be therapeutic.[19,21,22] It may also lead to reduction in healthcare use.[23] It was therefore encouraging that so many practitioners appeared to see it as their responsibility to deliver the PNES diagnosis face to face. However, few professionals, especially in MI and LI countries, reinforced the diagnosis by writing to patients, handing out leaflets, or referring patients to information websites or patient groups.[24] Similarly, many practitioners in LI countries stated that they do not communicate the diagnosis to other healthcare professionals, potentially increasing the risk of inappropriate (re)diagnosis of epilepsy or other paroxysmal disorders.

4.5 | Therapeutic strategies

A high proportion of practitioners reported that they offered at least one follow-up visit after diagnosis. However, 20% of respondents from HI countries reported not doing so. The most important reasons given for offering follow-up were narrowly neurologic: comorbid epilepsy and antiepileptic drug withdrawal. Given the importance of patients' acceptance and understanding of the diagnosis for the outcome of the disorder it could be argued that all patients should be offered more than one opportunity to discuss any doubts they might have, to reduce the sense of abandonment, and to facilitate engagement in further treatment.

Although the evidence for effectiveness of psychological therapy for PNES remains limited, with only a handful of uncontrolled studies,[25,26] growing evidence from pilot controlled trials of cognitive behavioral approaches exists,[14,27] and a recent meta-analysis has confirmed the likely effectiveness of this treatment modality.[28] In keeping with this, most professionals in all countries considered psychotherapy the treatment of choice. The results of a fully powered trial of cognitive behavioral therapy (CBT) for PNES currently being conducted in the United Kingdom and the availability of a manualized therapy for PNES should encourage more providers to facilitate access to this treatment modality.[29,30]

Only 5% thought antidepressants to be the best option, reflecting the limited evidence for the effectiveness of medications for PNES.[31] Of note, 40% of Japanese respondents thought that "environmental control" was most effective. This term refers to an approach that aims to reduce pressure on the patient by changing their environment (for instance by working with employers to modify expectations at work or with family members to reduce stress at home) and could be explored in other cultures.

4.6 | Etiologic factors

An integrative model emphasizes the interaction of a wide range of factors in the etiology of PNES.[32–35] Consistent with research evidence, our respondents most commonly recognized trauma and mental health issues as etiologically relevant. However, it is interesting that trauma was considered relevant less commonly in LI countries than in HI countries. There were also marked differences in the reported importance of trauma between different HI countries: For instance, the etiologic factor thought to be most prevalent in the prior Chile/US comparison survey was anxiety (34.4%), only 5% of participants were thought to have experienced significant "trauma"—in contrast, respondents from the United States estimated that 44% of their patients had been traumatized.[15] This demonstrates that perceptions of etiologic factors for PNES differ between cultures. To establish whether there are true differences in the etiology of PNES in different cultures, factors such as trauma would need to be measured at the patient level, rather than estimated by medical practitioners. Not surprisingly, poverty was cited more often as a significant factor in LI countries (40%) than in HI countries (10%).

4.7 | Obstacles to access care

Many respondents from LI countries reported financial problems as significant obstacles to diagnosis and treatment, with at least half of patients having to pay the entire cost of their health care. However, stigma, lack of popular awareness (70%), and lack of information (60%) were more commonly listed around the world. These obstacles should be less dependent on financial factors. This finding suggests that educational strategies may be helpful.

Lack of access to diagnosis was nonetheless reported as an important barrier to treatment, affecting an estimated 80% of patients in LI countries and nearly 50% in MI and HI countries. This included lack of access to practitioners capable of recognizing PNES, and lack of access to seizure experts. This suggests that more effort needs to be made in HI countries, by organizations such as the ILAE, to improve training in the recognition and treatment of PNES and to ensure that funders, insurance companies, and commissioners of health care are aware of the needs of patients with PNES.

4.8 | Limitations

Although this study is based on many survey responses from clinicians around the world, it has limitations. Despite this, we were less successful in collecting responses from LI countries. The data sets from HI countries allowed for the detection of regional differences that the LI datasets did not. Although respondents to the short survey were asked to bear in mind the situation in their country at large, rather than their own center, data provided by them (or by the small number of respondents from some large countries) may not be representative of the situations in their respective countries. We pooled responses from countries in 3 World Bank socioeconomic country categories to address this, but ranking of countries based on income ignores potentially important sociocultural, political, and historical differences that may have effects independent of economic status or healthcare system. Our open and mostly Internet-based, sampling strategy may have introduced other biases, favoring younger or urban respondents, for example. The fact that 80% of respondents to the long survey described their practice as hospital-based provides some evidence for this sort of sampling bias. This bias may have contributed to our finding that there were more responses in HI countries by highly specialized, senior professionals who felt more confident in the diagnosis of PNES and who made more diagnoses per year. We did not give respondents the opportunity to differentiate between services for particular subpopulations of patients with PNES such as children, older people, men, or individuals with intellectual disabilities or additional epilepsy. Prior to the administration of this survey globally, similar surveys had been administered to hundreds of providers in the United States, and Spanish and Portuguese translations of the earlier survey were

TABLE 2 Priorities for improvements in diagnostic and treatment services for patients with PNES around the world

Domain	Priorities
Practitioner knowledge/expertise	• Development of web-based, accessible training resources for practitioners to increase knowledge of PNES, facilitate diagnosis, and reduce prejudice, misconceptions, and stigmatization. • Definition of knowledge/skills related to PNES for inclusion in training curricula for health professionals in neurology, psychiatry, neurophysiology, and psychology.
Diagnosis	• Negotiation of an internationally accepted definition and nosology of PNES. • Development of diagnostic instruments for areas with no access to EEG/video-EEG (eg, home/smartphone videos, structured questionnaires, showing witnesses videos of typical epileptic seizures or PNES to improve diagnosis). • Development of diagnostic standards for PNES supporting the creation of better access to video-EEG including ambulatory video-EEG (especially in HI and MI countries).
Communication	• Development of web-based training resources for the communication of the diagnosis of PNES. • Provision of a repository of written information about PNES for patients, caregivers and healthcare professionals. • Supporting access to PNES information websites (eg, www.nonepilepticattacks.info, www.neurosymptoms.org, www.lareponsedupsy.info/CPNE (in French), www.neurokid.co.uk (for children and adolescents) http://www.epilepsy.com/learn/types-seizures/nonepileptic-seizures-or-events and creation of similar websites in other languages.
Treatment	• Development of defined treatment standards for patients with PNES to facilitate development of treatment services, especially in HI and MI countries (eg, level 1—communication of diagnosis, level 2—psychoeducation, level 3—individualized outpatient psychotherapy, level 4—individualized inpatient treatment). • Creation of a repository of treatment materials to facilitate the dissemination of available therapies to epilepsy centers and seizure treatment providers. • Development of structured interventions suitable for delivery by members of the healthcare team with limited training in psychotherapy (such as nurses or social workers). • Supporting the development of self-help resources or interventions requiring minimal therapist input.
Research	• Support of more in-depth research about differences in PNES manifestations, neuropathophysiologic mechanisms, etiologic factors, illness perceptions, societal attitudes, and management in different cultures to improve understanding and management of PNES. • Repeat of global surveys of diagnostic and treatment provisions for PNES to support service developments globally. • Promotion of fully powered, randomized therapeutic trials.

administered in Chile and Brazil, providing a foundation for administration to a global sample. However, the current surveys were carried out in several languages and completed by different health professionals who may not have understood all questions in the same way.

5 | CONCLUSIONS

Despite these limitations, this first Global PNES Provider Survey allows us to draw some clear conclusions. Although healthcare practitioners' perceptions of the etiology of PNES differ, the responses from a total of 63 countries demonstrate that PNES do not occur only in highly developed countries. Around the world, psychological therapy is considered the treatment of choice for the disorder, although professionals face many barriers to the provision of this treatment. Whereas financial difficulties were most problematic in LI countries, stigma and lack of information were the most common problems worldwide. Based on this survey, the ILAE PNES Task Force has formulated priorities for the improvement of the diagnosis, communication, treatment, and for future research (see Table 2).

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DISCLOSURE

None of the authors have any conflict of interest to disclose. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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